

*Next Meeting – Monday, November 6, 2006 – 2 PM
Appoquinimink State Service Center
Middletown, Delaware*

**STATE COUNCIL FOR PERSONS WITH DISABILITIES
BRAIN INJURY COMMITTEE
September 11, 2006 – 2:00 PM
APPOQUINIMINK STATE SERVICE CENTER
MIDDLETOWN, DELAWARE**

PRESENT: John Goodier, Chair; Brian Hartman, Co-Chair; Ann Phillips, Parent; Dianne Bingham, DPC; Ray Brouillette, Easter Seals; Jim Burcham, Consultant, BIA of DE; Dr. Jackie Christman, DPH; Dr. Jane Crowley, A.I. DuPont Hospital; Adam Fisher, DOE; Malik Harris, DelArf; Linda Heller, DSAAPD; Tony Horstman, SCPD; Lora Lewis, DPH; Chris Long, DDDS; Walt Mateja, DPH; Liz Schantz, Consumer; Mary Soligo, Christiana Counseling; Wendy Strauss, GACEC; Kyle Hodges, Staff, and Linda Bates, Support Staff

ABSENT: Virginia Corrigan, Christiana Care; Aaron Deede, Consumer; Dr. Dan Keating, Bancroft Neurohealth; Janet Leitch, Consumer; Michael Merrill, VR/U.S. DVA; Beth Mineo Mollica, DATI; Tom Parvis, DVR; Al Rose, DDC; Beverly Stapleford, CDC, and Dawn Stewart, Healthy Living

CALL TO ORDER

The meeting was called to order at 2:00 PM.

APPROVAL OF MINUTES

On page 5 under Concussion Card “Roll Out”—bullet #1, the percentage should be changed from 00% to 100%.

Motion was made, seconded and approved to accept the July 11, 2006 meeting minutes as amended.

AGENDA ADDITIONS/DELETIONS

- Linda Heller added Pediatric Trauma Webcast hand-out.
- Brian added the Maternal Health Child Services Block Grant Program.

BUSINESS

PATI Report

I. MENTAL HEALTH DRUG DEFINITION

In 2005, DMMA agreed to “grandfather” mental health drugs within its Medicaid formulary (a/k/a preferred drug list). The Medicaid Director agreed to consider SCPD input when establishing a definition of “mental health drug”. The SCPD and DMMA exchanged proposed definitions over the last several months. On August 22, Kyle and Brian reached consensus with the DMMA on the attached standard subject to revision to address memory enhancers apart from cholinesterase inhibitors. The positive outcomes from that August 22 meeting include the following: 1) application of the “grandfather” provision to new Medicaid beneficiaries; and 2) treatment of epilepsy as a mental health condition for purposes of the “grandfather” provision. Apart from some weak grammar, the definition is fairly encompassing. Since the DSM IV covers dementia due to head trauma (§294.1), TBI-related medications should be protected.

III. TBI CORRELATION WITH DEPRESSION

Brian provided an article from the August, 2006 edition of Massachusetts General Hospital’s Mind, Mood & Memory Newsletter. It describes multiple studies linking depression to TBI. A recent University of Iowa study found that 1/3 of TBI survivors were diagnosed with major depression within one year of injury. This correlation underscores the prudence of “grandfathering” TBI-related medications in the Medicaid formulary.

Chris said that the injury itself causes a bio-chemical imbalance in the brain as well as Situational depression.

III. U.S. SUPREME COURT DECISION: MEDICAID LIENS

The U.S. Supreme Court recently issued a favorable decision in the context of Medicaid liens. Arkansas Department of HHS v. Ahlborn, No. 04-1506 (May 1, 2006).

A college student suffered a TBI due to an auto accident which was not her fault. Medicaid paid over \$215,000 for her medical care. She had claims valued at \$3,000,000 against the driver at fault which she settled for 1/6 of the full value (\$550,000). Medicaid claimed a lien of 100% of its outlays (\$215,000). The consumer countered that Medicaid could only recover 1/6 of its claimed amount (\$35,000) since that is the proportion of full value that the consumer received.

The Supreme Court agreed with the consumer. For tort settlements, Medicaid can only recover a proportionate share of any recovery. This is helpful to TBI survivors who can retain a larger amount of settlements without having to repay disproportionate amounts to the State Medicaid agency.

IV. PROMISING NERVE CELL DEVELOPMENTS

Brian provided an article from the August, 2006 edition of Popular Science. Scientists have developed a method to facilitate reconnection of nerve cells. Oftentimes, nerve cells severed through TBI do not reconnect. Researches have now developed

connective trellises (“nanoscaffolds”) created with amino acids. When the vision tracts in hamsters’ brains were severed, and “nanothreads” were injected, 75% of the rodents regained sight.

V. DELAWAREANS WITH SPECIAL HEALTH NEEDS: MEDICAID MANAGED CARE PANEL

The above panel was formed several years ago to provide a forum for consumers and DMMA to discuss disability-related issues within the context of the Medicaid managed care system. The Panel has traditionally focused on children’s issues. Brian noted that the BIC’s agenda contains a heading for ABI Pediatric Services. Persons interested in the responsiveness of the Medicaid managed care system may wish to participate in Panel meetings. Meeting information is attached.

Brian noted that there is a meeting tomorrow October 12 at 10 am at AI DuPont Hospital for Children in Wilmington or the DuPont Pediatrics Clinic in Dover.

VI. TRAINING

A. ARC/DDDS Training

Consistent with the attachment, the ARC and DDDS are cosponsoring training on the DDDS service delivery system. Participants will receive an extensive training manual. Sessions are offered free of charge.

Kyle noted that the trainings are offered in Kent Co on September 26, New Castle Co on October 31 and in Sussex Co on November 17th—please see attachment for registration information.

B. Interviewing Techniques

Consistent with the attachment, CLASI is offering half-day training on September 15 to address interviewing techniques for difficult clients. If advocates from other agencies (e.g. BIA; NAMI) are interested in attending, 15 spaces were still available as of September 8

Brian noted that there is space available.

VII. AGGRESSIVE DRIVING CAMPAIGN

As reflected in the accompanying July 31, 2006 article, Delaware police have adopted a 6-month “Stop Aggressive Driving” campaign effective July 5, 2006. The Delaware Office of Highway Safety reports that 55% of fatal accidents in Delaware are attributable to aggressive behavior.

ABI Waiver Update

Kyle gave the following update:

- Allan, Larry or Scott could not be here—however, please refer to the hand-out in today's packet of information. This is a summary of their overview that they gave to us at the July BIC meeting. If you have any questions on this overview, they can be given to Larry or Allan.
- Linda Heller said that DSAAPD is having a meeting tomorrow on Benefits and the Definition of TBI. National, regional and Delaware consumer and providers' research has been completed and now they all need to decide the actual definition and the services that they will be putting into the waiver.
- Re: the definition, please refer to the July 21st letter (hand-out) which is a result of our last meeting. It was agreed that a sub-group of Brian, Tom Parvis, Adam, Jane, and Mike Merrell would meet to go over this survey. This group met and this is a response to Allan regarding our recommendations.
- Chris asked how is inappropriate behavior that is a result of TBI going to have an impact on what is being developed and what kind of services are available? Linda responded that behavioral services will be addressed in the waiver; however, she has not seen the recommendations. Chris inquired about the Peachtree services. Linda commented that, at Peachtree, there is no on-going interventional services and we are hoping that this will be resolved with the Assisted Living portion of the waiver.
- Brian commented that we will send out an invitation for Allan and Larry to attend the next Committee meeting.

ABI Implementation Grant Update

Walt, DHSS/DPH, gave the following overview:

- Walt introduced Lora Lewis as the new grant project director.
- An interim progress report was submitted for August.
- Lora attended the National Association for Head Injury Administrator's conference in Baltimore which was a very good starting place for Lora to learn about brain injury.
- Kyle commented that for the DOE TBI training in April, we had asked Walt if BIC could use some of the \$5,000 which has been set aside for a conference. It has been suggested to fiscally transfer and house the \$5,000 with the SCPD to support the conference. This is in the process of being transferred now through SCPDs fiscal section.
- John has put in for a new grant from the Developmental Disabilities Council.
- Normally, DSAAPD has contributed \$2,500 as a sponsor to the BIAD Conference.
- Lora said, to her knowledge, the \$5,000 is targeted for the BIAD conference in October. Lora said that there are other ways to support the DOE TBI training in April.

- Walt said that we can do a budget amendment and as long as it is less than 10 % of the total grant dollars, we do not have to go to the Feds.
- Kyle said we should do a conference call (Jane, Brian, Wendy) before our next BIC meeting to discuss this issue. We need to get an estimate of what we will be spending in April
- Brian announced that the BIAD conference is on October 25 at the Sheraton.

Anne Phillips, Center for Disabilities Studies (CDS), gave the following overview on the needs assessment:

- A new timeline will be given to Lora.
- Anne is contacting providers for data and then doing a survey.
- Brian said that since the BIC is the Advisory Committee, are there any plans for the Committee to see the draft findings for input? Anne commented yes.

Strategy for Helmet Bill (formerly SB 58) in the Next Session

Brian said that this was an initiative for the BIC. We introduced SB 58 two years ago which got through the Senate but not the House. There were a number of procedural things that happened to the bill which may have been unrelated to the merits. The substance of the bill is still apt—it would update the Code in terms of what standards the helmets have to meet and it would raise the age that kids have to wear a helmet if they are riding a bike, moped or an electronic scooter (which can go 35 mph) from the 16th birthday to the 18th birthday. It is still doable; however, we are going to have to get sponsors. From the House, Rep. Buckworth was the sponsor—however, he has retired, and from the Senate, Senator Margaret Rose Henry. Brian asked if we should re-introduce the bill and do you have any idea who would be the sponsors? Kyle suggested that we run this by Senator Henry. John suggested Rep. Oberle. Linda suggested asking Trish Roberts from the Director of Highway Safety, who is supportive of this bill, and also the Trauma System Committee of which Trish Roberts is a member. Brian said that the Division of Public Health originally endorsed the bill so we would want to get them to re-endorse the bill.

ABI Pediatric Services—what happens to those under 18?

- Kyle said that as a result of our last meeting talking about the DSAAPD waiver providing all these services to adults, Jane had a question of how we can address kids that are not eligible for this waiver. Jane said the other issue was the possibility of people that are injured before the age of 18 being excluded from participation when they reach age 18. The other piece is that there does not appear to be any plans at all in the State for the range of pediatric brain injury.
- Kyle said that re: injury before the age of 18 and then after the age of 18, he thinks that DSAAPD followed up in an e-mail shortly after the July meeting. Kyle will re-check for the e-mail. If it didn't get answered, Kyle will e-mail Allan.

- Linda said that the Feds are pushing for freedom of choice. The Feds may like it if the person has the choice of remaining with the DD waiver or moving to a different waiver. Jane said that they have never had a kid qualify for the DD waiver.
- Kyle said that he had a meeting before the legislative session ended with Reps. Hall-Long, and Ennis, Joe Keyes and Roy LaFontane because there was a case in which an individual was falling through the cracks. Joe and Roy said that they will be doing their eligibility criteria through their strategic plan in August. Kyle asked how we could have some input into the plan since we have been working on this for three years. Joe replied that they have not worked out the details but they will be soliciting input and feedback on how the eligibility criteria should be revised. This will be done as part of their development of revised criteria; and then of course there is the formal public review process as required by APA. Kyle is following up to make sure that the BIC is kept in the loop. This is one state agency that may cover kids with TBI if the eligibility criteria is written in such a way. Brian said that we have Child Mental Health (CMH) that has agreed to cover kids that meet their criteria. Jane said that she didn't know if they had been tested to get someone covered. Brian said that a decision was made that kids with TBI can qualify for Child Mental Health Services.
- On a preventative level, Jane asked if there would be a benefit for the BIC to issue a letter to CMS's Director Susan Cycyk asking them in a direct way to state that is the case. Brian and Linda felt that there was some kind of communication from Susan in writing on this issue. Kyle will check back to see what Susan's written response was to this issue. Brian commented that they still have to meet other criteria which means that health insurance or Medicaid have exhausted their coverage. So, there are some limitations in the CMH system. Also, there is still the school system that provides school health services. Jane said the big issue with the schools is that their center will take the kids for part of the day. The issue has been the behavioral or the impulse orders that exist that impact the families functioning outside the school hours. Other states offer, in their mental health system, is wrap-around services (e.g. some sort of assistance with the parents in the home). Brian said that one thing we could do is to contact CMH and say that there are some agencies that specialize in this population (e.g. DVR) and they have teams at CMH that could pair a psychologist with a DVR case manager—is it possible that they would develop that kind of a model? So then you would have a point person to be talking to. Jane said that would be great if we could have that kind of access. Brian reiterated that there was a subsequent CMH initiative where they went through strategic planning and the consultant put into the report something to the effect that they should not cover TBI. We objected to that, and CMS took it out. Brian said that, strategically, if you are not seeing that the system, as a practical manner, is a great asset to the kids with TBI, maybe we should engage in some dialogue to make it more responsive. One way is to see if they would designate one team in each County to specialize in the TBI population. It is hard to develop expertise in all mental disorders. Jane said there is an issue of how you go back to reach the persons that have been years without services to tell them that they may be able to avail themselves of this service.

There are people who have given up. Jane said it would be beneficial to have a letter in hand stating that there is access the system since we have tried to access the system in the past and have been rejected. Kyle said that he knows it is in the meeting minutes; but he is not sure if CMH sent a formal document and he will check on that. Jane suggested for Kyle to wait and write a letter until she has some experience with the revised system. Kyle and Jane confirmed that Kyle would get Jane the minutes and any other documents, but wait on sending a letter until someone is sent through the system.

Brian asked Chris to follow-up with Sue Cycyk to see if there is something from CMH to see if they will take kids with co-occurring autism or mental retardation or TBI plus. Chris said that she did a MOU boiler plate outline and then handed it to Joe Keyes for more specific expertise. Chris will check what the status is of this MOU.

Chris noted that a consumer should not have to call nine agencies to figure who would serve the person with a disability. There needs to be a single point of entry. Kyle noted that the Money Follow the Person grant application is trying to incorporate this or something similar. Linda said some states use the Brain Injury Association and then their case managers work with the families and feed them into the correct agency. At least one 800 number is called and they get the support or respite or whatever they need right away.

Ann Phillips said that the “Connecting the Dots” book is going to be printing at the end of this month. With the collaboration of CDS, DFRC and the DD Council, this is a booklet for families to use to navigate the system depending what the needs are either educational, financial, medical or legal. This book is being distributed to all agencies where families are calling.

John asked if certain states that are using the BIA are making a financial contract with their BIA for financial help? Linda replied “yes”.

Chris said that at one time all the kids were housed at the Stockley Center. The Department of Education has is now enhancing special education services and the provision of a private public education which would include residential services. Someone took that role and mitigated it for the role that Stockley had played for children. Chris said that DDDS is working on the MOU with CMH. In speaking with Sue Cycyk last week, CMH has a psychiatric fellowship with Thomas Jefferson Medical School. So, we are looking into these types of things so we can enhance our services.

Linda said that there is a line in the grant that “one of the jobs is to explore a pediatric TBI waiver”; or figuring out if we can enhance other waivers or services in the State by doing an assessment.

Jane suggested that we put this on the next month's agenda to explore what kind of services that we can develop. We could have a parallel system to what we have in the pipeline for adults. Ann replied that she can also include this in the needs assessment survey. So, we could put this in the needs assessment report and get feedback from all the providers.

Jane noted that there is a huge need at all levels (e.g. hospital, etc.) for education on TBI. Brian noted that Allan presented that this waiver is not going to be a DSAAPD waiver and that it is going to be administered by DMMA. Linda noted that all waivers are going through DMMA. Brian said that we really should be pushing for this waiver to cover adults and tie in CMH and not just DSAAPD at the planning stage. The age range of the waiver can be lowered as it hasn't been finalized yet. Linda noted that DSAAPD is now amending the Assisted Living and Elderly and Disabled waiver so it may be difficult to expand to include pediatric services. Brian replied that you can waive age. Ann asked who would administer the services under age 18? Brian said it could be CMH and/or DDDS. It was noted that many kids get head injuries between 16-18 years.

Brian suggested that we write to DSAAPD and say we had a discussion on pediatric services and there does not appear to be a lot of waiver supported services for kids. The Diamond Health Plan covers adults and children and various kids and adult agencies support this plan. We would like to do that with this waiver. Maybe the consultant knows if other states E & D waivers work this way.

It was decided that Kyle would ask Allan and Larry to give us an update at our next meeting regarding the supplement to our age recommendations.

Motion was made, seconded and approved to send the letter as suggested. Linda Heller abstained.

NJBIAD Presentation

Jane had suggested that New Jersey BIAD come and make a presentation to the BIC.

Jane informed us that the New Jersey BIAD has secured a wonderful funding mechanism which includes a fee that is assessed on every drunk driving which gives everyone \$10-15,000 a year for health expenses that are not covered or for those who have maxed out their medical policy. Linda said they also receive so much money when people purchase New Jersey tags. This would give us an idea of a state that has a pretty good service system in place. Of the four states that the hospital deals with, Jane said that they are the most sophisticated and the best organized. They were very successful in getting this funding that really works for the services that kids would not get otherwise. Kyle said that he has a contact of Mary Beth Diehl from the southern NJBIA from Jane. Jim Burcham also said that Barbara Geiger Parker is the Executive Director from the NJ BIAD. Linda also said that there is a funding stream document from the National TBI

Technical Assistance Center that could be sent to all members of the BIC before the next meeting.

Kyle will contact Barbara Geiger Parker to determine if the NJBIA can attend a meeting.

Concussion Card Presentations to Football Coaches

The following was discussed.

- Five hundred concussion cards have been received from Jane
- In August, Kyle and Jane went to Rules Clinics to make a presentation of the concussion cards to coaches. Both were well received and people were appreciative. Kyle had about 40 coaches at his presentation and Jane had about 30 coaches at her presentation. Someone also handed out the cards to officials at Jane's session.
- Jane said that the coaches cannot really see what is going on that well since they are at field level with the players. An official said that they are more likely to see the consequences of two players being hit; therefore, the officials need this education as much as the coaches.
- Jane said that there is a lot of education to be done as the coaches do not see this as a viable concept and that it really does not happen all that often.
- Jim asked if the trainers had been educated. Jane and Kyle replied they had not made a presentation to the athletic trainers. Dennis Rubino and Jane had done a previous presentation at the trainers' level. Jane noted that since they can be Master's level PTs, there probably is not as much education needed for them. The athletic trainers should be the arbiters if a person should come out of the game or return to play. Jane noted that the players should be educated as well. Kyle noted at the presentation the officials did show some slides on brain injury.
- Kevin Charles, the head of DIAA, said it would be useful to have this information made into a poster to be posted in the locker rooms, etc.. A draft is in today's hand-outs. Jane noted that the hospital is willing to absorb the cost. Kevin said about 400-500 posters would be sufficient to send to the high schools for locker rooms, athletic director's offices, etc. Also, since all parents of participating athletes have to come to a meeting each year that could be an audience to target. Jane said that the posters can be completed by October 4th. Kyle said that there is an Athletic Trainers meeting on October 4 at 9 am so we could include this in a presentation then. Jane said that she can be at this meeting.
- Jim received an e-mail from a young lady who is a senior at Wilmington Charter School. She has to do a senior research project on brain injury. After having 3-5 concussions, she can no longer play field hockey or basketball. She would be a great resource for student education.
- Kyle said that basketball and wrestling clinics are held in October. Jim agreed to help with the presentations on behalf of the BIAD.

Status of DOE Training

Kyle gave the following update:

- Wendy, Jane, Martha Toomey from DOE and Kyle had met to discuss the DOE training scheduled for April 10th from 9 am to 3 pm at AI DuPont. We need to determine the costs so we can determine where the money will come from. The audience would be broad—teachers, special ed directors, educational diagnosticians, and nurses. Wendy suggested having one in Sussex County if this one was not well attended.

Names of BIC Initiatives

Jane gave the following update:

- Regarding our concussion care initiative, Jane suggested calling it the “Delaware Concussion Initiative” and seeks out some publicity specific to that. AI duPont hospital has a good connection with the newspapers.
- Linda suggested that the Delaware Injury Prevention Coalition be involved. There may be some kind of support with their prevention activities. Their next task force meeting is coming soon. Linda will bring up the topic at this meeting.
- John asked if this is a sports concussion initiative. Jane said we could call it a concussion initiative, but say that we started with the sports concussion. However, Jane said that she has been contacted to talk to all the social workers for the Wellness Centers across the state on brain injury so that is broad. Jane said that she would probably pass this off to the business people at the hospital.
- It was asked if the reading level of the card was considered. Jane replied that they used the national brain injury language but, that was a good point. Kyle said that at the two presentations, the concussion cards included a back-up description. Jane said that this would not be distributed to parents or athletes as it is strictly for sideline management at this point.

Other Business

- Brian distributed a hand-out from the Disabilities Law Program on the proposed priorities for the protection and advocacy system for the individuals with mental illness (PAIMI), developmental disabilities (PADD), traumatic brain injury (PATBI), protection and advocacy for assistive technology (PAAT) and protection and advocacy for individual rights (PAIR) programs for fiscal year 2007.

Brian said that the Disabilities Law Program receives a grant to do TBI advocacy. Revised priorities have to be submitted to the Feds on an annual basis so this is the proposed set of priorities for the federal fiscal year beginning October 1st. This proposal has been put on our website and 100 copies have been mailed out to

various organizations/individuals soliciting public comments to be reported to the Feds.

On the website there are the five priorities. The priorities of various Councils may differ from the Disabilities Law program. Each Council has a different mandate.

For this Committee, Brian briefly reviewed the PATBI document as follows:

- Not much was changed in terms of the goals and outcome measures; most of the changes are in the rationale section.
- For example – Prevention - we kept the same standard and updated the information on the helmet bill. We anticipate driver safety bills being re-introduced again, and we mentioned our support for the concussion card initiative from this Committee.
- Special Ed is the same; however, we changed the outcome measure since we have been getting kids identified going from 0 in FY 04, 7 in FY 05, and 26 in FY 06, and targeting 30 in the next fiscal year.
- Health and Financial Benefits is the same; however under rationale, we indicate that we are going to work on the waivers that DSAAPD is amending to incorporate TBI. Regarding the Mental Health waiver, as we discussed today, we want to finalize that and help out with the TBI implementation grant. We also anticipate having to address TBI in the workers comp bill that is going to be re-introduced which will affect our constituents.
- Government Programs and Services is the same; however, we do anticipate that DDDS will revive its eligibility review - what is their criteria going to be for accepting people with TBI.
- The Equal Accommodations bill passed so that will be implemented.
- The Community Living and the Community Education is mostly the same except for a few minor changes.

Please get your comments to Kyle by October 18 so all comments can be put into one letter.

- In July, Brian noticed a legal notice in the newspaper. There is a Title V Maternal Child Health block grant program application filed by Public Health to the Feds for money. Some of it is for prevention among children. Brian asked Kyle to follow-up with Walt to see if there are TBI aspects in the plan or could we have input. Walt said it is a Federal Maternal Child Health block grant with funding of \$2 million a year. 35% needs to be spent on children with special health care needs. There are 18 national performance measures to be addressed and 10 state performance measures based on a 5 year needs assessment that was done last year. Walt noted that they are looking to post it on the web for next year and also to get additional comments for next year's application. Brian suggested that we

tickle this for June of 2007 when it will be on the web and we could review it and give some comments from the TBI perspective.

- Linda Heller referred to the Pediatric Trauma Internet web cast to be held on September 27. This will be held on-line with national speakers.
- Homelessness, TBI and Veteran's issues were brought up at the National Association for Head Injury Administrator's conference in Baltimore that Linda and Lora attended. Linda will distribute hand-outs from this convention at the next meeting.

ANNOUNCEMENTS

The next meeting will be held on November 6 at 2 pm at the Appoquinimink State Service Center in Middletown.

ADJOURNMENT

The meeting was adjourned at 4:15 PM.

Respectively submitted,

Kyle Hodges
SCPD Administrator